Summary
Disguised suffering: A care ethical inquiry into the late modern ideal of a 'succesful life'

What is this dissertation about?
My dissertation is about an urgent societal issue which I address with scientific inquiry. The issue at hand is that the broadly accepted conception of 'ordinary' citizenship lacks difficult, dark realities of actual people. The hegemonic idea of 'ordinary' citizenship is that of an autonomous free individual who designs his own life. He chooses how he leads his life, who he is or aspires to be. He directs and controls his life, health and well-being in a vital and active way. As an emotional being this citizen strives to grow, flourish and actualize himself both in the context of work and in the private domain. If he makes full use of his inner resources, the promise of happiness looms at the horizon. He himself is responsible for the outcomes of his choices and actions, his successes and failures. I argue that care and assistance are often focused on the recovery of autonomy and the freedom of this type of 'ordinary' citizen.

Compared to the ancient, top-down imposed conception of the citizen, this new, freely accepted 'ordinary' conception may seem like an improvement. Upon further reflection, tensions in aspects of the new conception are revealed, upon which I shine a light in my research. By focusing on the free-choice individual, this ordinary conception neglects the social reality where people are, in many aspects, inevitably unequal and not so free after all. A notion of self-responsibility that projects life as malleable (*maakbaar)*, neglects people who have never been, or will never again be vital or prosperous. Presenting health and wellbeing as malleable forgoes the reality that sickness, loss and suffering can and will eventually happen to everyone at (unelected) moments. What 'failure' actually means, reveals itself in the dark backgrounds of society, where dropouts are seen as losers who should be normalized. Individual autonomy and freedom paradoxically turn out to be both an aspiration and a normative duty. Broadly speaking, in the ordinary conception of the citizen the negative, difficult and bitter aspects of actual human lives are left out and the emphasis is put on the positive and the nice aspects. Here, I identify a large incongruence. Subjective experiences, which by definition are *not* malleable, are conceived as effecting actions.

This new ordinary conception of the citizen has ties to the collective protests in the symbolic school year of '68. Students (offspring of the bourgeois elite), feminists and laborers demanded changes from the hierarchical, patriarchal bourgeois that held the political and economic power. They wanted more freedom, self-determination and recognition as humans with feelings. The protests resulted in a cultural revolution and a process of democratization. During the 80's and 90's the democratized state launched a political ideal of creative-entrepreneurial citizenship. In some way this was a cultural-economic response to the aforementioned political demands of freedom and humanity. A large majority voluntarily agreed with this new, affective governmental discourse of the self-reliant citizen. Besides individuals, also the institutions in almost all social domains change in creative enterprises. Even the state positioned itself as an enterprise; a private company limited by shares. All in all this illustrates a profound transformation of a social liberal collective welfare state to a neo-liberal, individual self-care state. The fact that citizenship, patienthood and institutions, among which the healthcare system, lost their political nature plays a key part in my dissertation.

In 1991 the sociologist Anthony Giddens labeled this newly arisen era 'late modernity'. He describes late modernity as a dynamic, unpredictable, self-contradictory and conflictual hyperfase within modernity. In that new era, with unprecedented material surplus for the majority, culture and economy are focused on the production of the immaterial. Production and consumption no longer place the utility of products and services at the center, but rather the experiences and the enjoyment. From culture the economy derives how these immaterial experiences can be accomplished ('rendered mallable'). Esthetics, psychology, arts and humanities serve as important earning resources for this newly developed culture economy. In a further stage of development this culture economy enriches the production and consumption with the experiences of the ethically meaningful.

I call the ordinary idea of society that deeply penetrates and changes the social world a discourse (Marchart, 2013b). A discourse consists of the collection of images, stories, statements, metaphors and meanings. And of forms of communication, like aesthetically sensory stimulations and (psycho)social technologies. That collective represents *and* constructs the social reality; the practices of people and objects, such as material surroundings or technical aides.

Contemporary practitioners in sectors like education, welfare and health care primarily critique increasing dynamism and uncertainty (Rosa, 2016). The unlimited pressure to boost achievements, the continuous thrive for self-improvement (even though it's never enough), and the ever-expanding bureaucratic duties limit their ability to do proper work. In addition to this increasing dynamism there is the terrifying, sickening uncertainty about their position. Achievements are linked to social appreciation and status; retention of position to success and de-valuation to failure. Unconditional recognition as a citizen in the political society (*polis),* has been replaced in the culture economy by conditional appreciation. Citizens have precarious, losing positions. Strikingly, criticism from practitioners is not focused on the new 'ordinary' idea of total control of the self (including subjective experiences). It has become normal that 'the self', faced with 'abnormal' insecurity, exhaustion or unhappiness, recovers its vital, entrepreneurial 'normality' with the help of a broad selection of aid workers. I consider this notion of the 'ordinary' citizen as an urgent societal problem that concerns all.

From which scientific discipline do I conduct my research?

My theoretical framework is ethics of care as an independent, modernity-critical, political theory and ethics of caring. Ethics of care originated in the 1980s as a political movement and academic discipline. As a discipline, she has feminist roots; some of its founding mothers took part in the protest movement of '68 and subsequent civil rights movements. The first generation of care ethicists criticizes the dominant normative ethics and knowledge theory because concrete people, their struggles, concerns and moral experiences play no role in this. They develop an ethics of care. The second generation broadens this theory to a fundamental political theory of giving care and receiving care, which is a novelty. Care, informal and formal, is a humanizing and societal structure defining practice that keeps the lives of all going. At a societal level, care ethicists strive for a society in which care is given a central place. In academia they fight to broaden the boundaries in the prevailing abstract, individual-oriented, normative ethics. They want recognition for moral knowledge in lived, first person

experiences – with attention to their position in society – and they demand a realistic conception of people and coexistence.

Ethics of care proposes involvement as an explicit normative perspective on reality. Primarily it puts an (unwelcome) spotlight on people who usually work in the shadows and who lead adversity-laden lives. It analyzes difficult lives and suffering in a broad context of long-term social problems. It works with changeable critical insights, one of which is certain: people live in relationships, embedded in practices, and not as individuals. In my research I take the renowned Anglo-Saxon mainstream of care ethics as a starting point.

I employ a threefold problem definition, in multiple sentences, which showcases transformed citizenship, changed institutions and changed societies. Within those three layers I research, from the bottom up, what is going on and who does (not) benefit from it. That is an ethical (ethos) and political query. The political and the ethos are my framework of perceiving how coexistence is actually ordered or disordered (a political issue) and how that humanizes or de-humanizes (an ethical issue). I employ that register, alongside a number of queries and concepts, in my theoretical, conceptual research.

My analytical research framework is: citizen (patient), suffering (vulnerability), in late modernity. My approach is comprised of wanting to know more about how the citizen is currently perceived in the dominant societal discourse and what that means for the realities of human suffering.

How do I conduct my research?

In my theoretical and conceptual research, I employ a descriptive-analytical strategy, while postponing my judgment as long as possible. This entails a weakly normative, *Minima Moralia-informed,* strategy.

Ethics of care confronts me with the problem that it works within a paradigm of modernity and does not delve into late modernity, which requires a new scientific paradigm. It therefore misses the specific answer that has been given to, among other things, its own demands in '68. I still start with insights from ethics of care, but I also utilize other sources. In the works of some critical sociologists, I research how they discuss the dominant discourse and what, according to them, happens with citizenship, coexistence and suffering. These sociologist are deeply aware of the late modern era. Deep outrage about the demolition of the social and the arising precarity of human lives drives their sociological-phenomenological research. In addition I employ two other type of sources. In the exploratory part I of this research, I consult practitioners who, based on the their practical experiences in health care, speak in concerned and critical terms about the citizen discourse. Their patients mostly believe in full malleability and healthcare enterprises do not disagree with the patient-customer. In part II I research the public management literature, which is representative of the irreversible turn of experience capitalism to a new, broad dominant movement.

What is the structure of this dissertation?

After the introduction on chapter 1, this book is comprised of four parts each containing two chapters.

Part I offers a first exploration of discourses about vulnerability and suffering of citizens in care practices and ethics of care.

In **chapter 2** I make a plausible case for my societal problem statement on the basis of a number of care practitioners. It also form an obvious bridge to chapter 3 about ethics of care.

I showcase five experienced, critical practitioners working in hospitals and the mental health industry. In their publications, which are based on their practices, they express concern about the usual discourse of malleability of life, body, happiness and health. The realities of sickness, unhappiness, suffering, the unavoidable and the finality of life are not included in that discourse. Many patients expect, or demand recovery, a cure, even though that is by no means always possible. Their shared concern is that they are unable to conduct their work, to *help* the patient. The malleability discourse lingers in their care practices and this is caused by a complex set of reasons. As an urgent societal issue, they highlight the necessity of a *different*, realistic discourse about life and suffering. Using four questions that I derive from my problem definition I map what each of them brings to the table in terms of analysis of the problem (program) and possible ways out (counterprogram). I ask how they speak in their work about: 1. the current discourse about the citizen, the patient and society. 2. The usual *framing* of experiences of vulnerability and suffering. 3. The transformation of the institute of health care to an enterprise. 4. The dominant scientific and knowledge paradigm. I categorize them in a scheme 'Program-counterprogram'.

In chapter 3 I offer a state of affairs after 40 years of ethics of care. In general terms, ethics of care has represented a long history of political-societal and scientific neglect and contempt towards people who (have to) conduct care and people who are dependent of care. She denounced this denial of the constitutive importance of caring for the coexistence and survival of mankind. Ethics of care has caused a stir and has gained worldwide recognition. Currently however, many tendencies are manifesting themselves, both from the inside and the outside, that threaten its potential for critical reflection. In this chapter I identify both the irrevocable merit of ethics as care as well as the limitations it showcases in reflecting on late modern transformations. These limitations are made evident when I propose my questions to Joan Tronto, as an honorable figurehead, and three other prominent figures from the first generations of the Anglosaksian mainstream. It is problematic that ethics of care does not delve into the late modern epoch. In the 21st century, it distances itself from practices, its unique well of knowledge and origin. It turns in an ideological direction. For my issue, I encounter aporias and gaps in care ethics. To nonetheless be able to conduct my research from a care ethical perspective, I return to the original, thoroughly realistic founding mothers who are driven by feminism. I take their developed critical insights and some leads that have not been fully developed as a starting point. I complement them and bring them to "this day and age". In that way, I position myself within ethics of care and this research remains critical, political theoretical and ethical-epistemological.

Part II addresses the changed experience and perception of sickness and suffering in the late modern experience society. I discuss two accounts of the dominant discourse that, at first glance, look strikingly similar. Both accounts have a phenomenological research approach. They both develop theory in interaction with research in practices and they both coin the term "experience economy". The first of these perspectives on reality stems from cultural sociology and the humanities and leaves room for ambiguity. The other perspective is a human-centered

business approach. It is (natural) scientific and unambiguous. *De-facto* this leads to severe differences in how they approach and frame my issue.

To explore my issue more in-depth, **in chapter 4,** I take the discourse of the cultural sociologist Gerhard Schulze (1992) as a point of departure. He describes how the order between individual and society has been reversed in Western societies. Reluctantly, I follow his suggestion to start at the individual level and to primarily research happiness and subsequently study unhappiness. That is the happiness discourse of the supposedly 'malleable' self-design as the project of experiencing the beautiful, good life that the prosperous, overwhelming majority believes to be true. In the experience economy the "self" is placed at the center. Schulze illuminates why "social inequality" no longer suffices as an approach. He shows *how* experiencing life was able to become *the* goal in life. He explains what the notion of experiencing means in a causal (and amoral) framework. *How* unmalleable experiences were categorized under malleability. And which – distinguished – agency the creation of experiences, perception creation, demands from on the one hand individuals and on the other hand companies. Schulze reveals to what extent the focus on 'experiencing' in the new, multifaceted era of experien-cing, the social judgments, the pathological shapes and the perceiving and experiencing of misery have changed. Schulze's hypothesis is that society does not dissolve into separate individuals. A bottom-up reordering leads to five mutually distant, hard to discern, inward-oriented, choice groups of those who are likeminded in their style of experiencing. A split, almost horizontal experience society is shaped. One group, which Schulze calls the "self-actualization social environment group", origins from the cultural protest of the students in '68. This group plays a discourse decisive part in late modernity.

In chapter 5 I legitimize, based on the works of two renowned sociologists, my unusual choice for studying the genre of popular management literature. I call the authors of books in that genre "BME's" (Business-Management/Marketing-Entrepreneurs). They represent the irreversible turn to immaterial capitalism that prescribes new scarcity and endless markets for the economic value of emotion. In the works of these BME's I identify a very complex *and* insightful inside perspective. Scientifically, their work is abject, societally their influence is large; partially because they solve two -ongoing- problems with modernity. They call their own point of view humane-businesslike; their goal (*purpose*), the 'soul' of *all* enterprises, is to fulfill – business specific – costumers needs. The humane part involves that businesses put 'the human' (costumer and employee) at the center. The driver of their business is to accomplish the required perceptual experiences. In the first order of this form of capitalism, that means experiencing (enjoying). In the second (highest) order, the costumer wants authentic meaningful experiences (in life); they want to transform into a *better* version of themself. It is also towards that passioned purpose that companies, including hospitals, strive. Sickness and suffering, according to BME's, are part of transformation business. They present a business philosophy and ethics that serve mankind. Companies *and* people that help solve societal and worldwide problems, realize themselves. Human *and* economic worth melt together in a win-win proposition. The BME's frame their affective discourses as a liberation of authorities and institutions that impinged free agency. In parallel to the genesis of this form of capitalism marketing (which plays a key role) develops into branding and subsequently into mattering. The BME's portray a frictionless network society where a capitalistic vision of peace glooms at the horizon. Focusing on my issue, I map the structure of their argument.

Part III contains a current and in depth layer of ambiguity and darkness in the late modern freedom discourse.

In chapter 6 I focus on the political answer to the industrial times that have definitively ended. That answer is the fiction of a creative-entrepreneurial behavioral model of the citizen. Using three (cultural) sociologist I delve deeper into the problematic individual-identity creation issue (Jean-Claude Kaufmann) and the attractive behavioral modal of the *Entrepreneurial-self* (Ulrich Bröckling, Andreas Reckwitz). The origin of this discourse goes back to the bourgeois that splits into two fronts at the end of the 18th century; respectively the entrepreneurial versus the artistic-creative oriented. The three sociologists perceive the current discourse as a secular religion of the bourgeois and those who adhere to them. Reckwitz updates Schulzes thesis about large groups in society, 25 years after Schulze introduced it, with a thesis of an unequal democratic status society. A broad upper-class plays a decisive role in the internalizing of the cultural hegemonial discourse that places citizens at uncertain, conditional positions. This class also plays a large part in the positive psychological care to dropouts, who are empowered to become creative entrepreneurs. This academic class holds the life styles of the 'lower' classes, among which the survivors at the edge of the abyss, -more or less subtly- in contempt. They disregard the daily struggles, the resourcefulness, creativity, the agency and the knowledge of these survivors.

The latent conflicts among the large groups Schulze identified has grown into a political crisis; a battle field of multiple cultural-identitarian communities. The harmony-oriented upper-class does not identify connections between the minimalization of state function, the maximalization of entrepreneurial politics, the precaritization of citizens, new pathologies and polarization of enraged citizens that battle for their identities and unconditional recognition. It looks like a dark, bleak situation in a deranged society. The myth of the individual that shapes their own identity remains, however, unassailed.

In chapter 7 I introduce the sociologist Oliver Marchart. He shares the analysis of his colleagues (chapter 6) *and* sees a possible way out of the regime of the citizen discourse. He calls precarity politico-economically produced vulnerability. Precaritization, as existential insecurity, extends far beyond the realm of labour and disrupts relationships and society. Through almost *all* classes, ranging from cleaners to 'modern proletary academics', a new broad class of precarious people who share losing positions emerges. Marchart studies discourse- and hegemony theory. The affective discourse in the current, neoliberal cultural hegemony is a form of power without a discernible center. As an authority of belief it settles inside the individual that subjects itself as an enterpreneurial-self that is at once both boss and servant. This discourse ridicules the social, tears down institutions and portrays reality as unchangeable. From a historical perspective of modernity, Marchart shows that protest movements that combat hegemony do bring along change. Neoliberalism negates contingence, conflict, the political and (ontologically) assumes a harmonious whole. All these aspects constitute an ideology. Using a metaphor of trenches, Marchart illustrates in what ways a society with identitarian forces differs from the protests in '68. Then, laborers fought against bosses and feminists against patriarchy. But in a battle of theses, it is unclear, diffuse, who are friend and foe. Protest movements can break a hegemony if they unite themselves in a *post*-identity way around a shared urgent issue and – peacefully – engage in the conflict. Marchart gives incitements for a

theory of society that is *open* to change. With two cohesive diagnoses of society, he critiques the entrepreneurial self *and* offers a way out. The state of affairs is dark, frightening, but not hopeless.

Part IV consists of both care ethical insights and research findings as well as a thetic part of propositions to ethics of care.

In chapter 8 I synthesize ethics of care and my research findings. From an care-ethical perspective I judge my analytical findings and deepen my three-part problem statement. I make this judgment using the care ethical treasury; insights from the early ethics of care and some additions that I (theoretically) updated.

I consistently shift focus between on the one hand zooming into 'my issue', citizen (patient), experiences of suffering; and on the other hand zooming out on institutions and society that dis-organizes and re-organizes. These transformations occur against the backdrop of late modernity.

My register of perceiving is, as much as possible with a literature review, the political and ethos. I pay extra attention to how relationality, community, care/caring, power and class are manifested. I take the current, broadly accepted, citizen discourse of 'normality' as a point of entrance. After a short refresher of the care ethical merits, the categorization of societal diagnoses and characterization of late modernity, I conduct the synthesis. 1. Elaboration of the (genesis) of the current conception of citizenship. 2. Clarification of the framing of experiences of vulnerability and suffering, patienthood and agency in care practices. 3. Novel relationality and coexistence, new classes, new power and the preservation of the *good* of modernity. For each of these three I provide initial attempts for care ethical social imaginaries that are different from the prevailing social imaginary. After my elaborated problem statement I ask a number of (self) critical questions to care ethics. In two pointes I condense what I believe to be the main reasons that care ethics is losing critical power.

In chapter 9 ethics of care is the recipient of my propositions. The propositions offer a possible direction for ethics of care to leave its aporetic situation and reutilize its critical potential. Following this direction, it can again be beneficial to issues in late modern practices and can develop actual, realistic and provisionary political theory and ethics. My propositions boil down to ethics of care recovering its bind to practices, its essential source of moral and political knowledge. The first two proposals are in a way the preparation for exactly that. Ethics of care distances itself from *late turns* that nullify its unique position. And, ethico-epistomologically it unmistakably takes position in the field of ethics. The third proposition involves a – principally – tangible and concrete research proposal for practices that has been tested by Dutch care ethicists. My fourth proposition follows partly from the third; ethics of care, as an autonomous discipline, strengthens its cooperation with fellow travelers. Finally, I present my social and scientific research claim, which I defend as legitimate and appropriate within care ethics. I also describe some limitations and shortcomings of this research.